



DementiaUK
Helping families face dementia

Volunteer Ambassador

FAQs

What is dementia?

Dementia is an umbrella term used to describe a range of progressive neurological disorders, that is, conditions affecting the brain. There are many different types of dementia, of which Alzheimer's disease is the most common. Some people may have a combination of types of dementia. Regardless of which type is diagnosed, each person will experience their dementia in their own unique way.

Symptoms of dementia can include:

Memory problems

People with dementia might have problems retaining new information. They might get lost in previously familiar places and may struggle with names. Relatives might notice the person seems increasingly forgetful, misplacing things regularly. However, we all forget a name or face once in a while and this is nothing to worry about. If it happens on a frequent basis, it's advisable to visit the GP who can check why this may be happening.

Cognitive ability, i.e. processing information

People with dementia may have difficulty with time and place, for example, getting up in the middle of the night to go to work, even though they're retired. Also their concentration could be affected. There may be a difficulty when shopping with choosing the items and then paying for them. For some people with dementia the ability to reason and make decisions may also be affected. Some people with dementia get a sense of restlessness and prefer to keep moving than sit still; others may be reluctant to take part in activities they used to enjoy.

Communication

People with dementia may repeat themselves often or have difficulty finding the right words. Reading and writing might become challenging. They might experience changes in personality and behaviour, mood swings, anxiety and depression. People with dementia can lose interest in seeing others socially. Following and engaging in conversation can be difficult and tiring, and so a formerly outgoing person might become quieter and more introverted. Their self-confidence might be affected.

Dementia can be seen as a combination of one, or all of the above symptoms. If you or someone you know is experiencing one or more of these symptoms, which have been occurring for a while and are progressively getting worse, then please arrange a visit to the GP. There are many other reasons someone might be experiencing confusion or memory problems, so it is best to get them checked out and treated if necessary.

What is dementia? And what's the difference between dementia and Alzheimer's?

There are over 200 different causes and types of dementia, of which Alzheimer's disease is the most commonly diagnosed. Other common types of dementia include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.

Alzheimer's disease

Alzheimer's disease is the most common type of dementia. It changes the structure of the brain and affects the chemicals that are responsible for transmitting signals between brain cells, which means that nerve messages aren't passed on correctly. The most common and noticeable symptom is short term memory problems, with other symptoms including difficulties with finding the right words, solving problems, making decisions, or perceiving things in three dimensions. Signs of depression or irritability may also be seen together with a loss of interest in activities.

Vascular dementia

Vascular dementia is the second most commonly diagnosed dementia. The brain, like all other cells in the body, needs a regular supply of blood and oxygen. If this supply is affected in any way the cells suffer damage. When these brain cells no longer function properly a person may develop vascular dementia.

Some areas of the brain may be more affected than others, and some areas of the brain may remain relatively unaffected. People with vascular dementia, as a result, may be acutely aware of problems they are experiencing, more-so than with other types of dementia, and this can lead to an increased risk of depression. As vascular dementia affects different areas of the brain, there is not a defined way of experiencing it. The symptoms are similar to those of other types of dementia, however it doesn't progress in the same way. A person's cognitive function may remain at a constant level for a period of time, and then very quickly and obviously decline before plateauing again.



Dementia with Lewy bodies

This type of dementia takes its name from abnormal collections of protein, known as Lewy bodies, which occur in the nerve cells of the brain. In addition to the symptoms of Alzheimer's disease, people with Lewy Body dementia are likely to experience hallucinations. The condition tends to fluctuate and can include symptoms of Parkinson's disease such as difficulty walking and becoming unable to balance. This condition often progresses more rapidly than Alzheimer's disease.

Frontotemporal dementia

In frontotemporal dementia, the front and side parts of the brain are damaged over time when clumps of abnormal proteins form inside nerve cells, causing them to die. People who are affected by frontotemporal dementia (including frontal lobe dementia) may not have the type of memory problems normally associated with other types of dementia. The most common symptom is a change in behaviour and personality. For example a person who was previously very quiet and unassuming might become loud and aggressive and use offensive language. Some people become withdrawn, while others may become disinhibited or even sexually inappropriate and may exhibit sexual behaviour in public. The person may also have difficulties with fluent speech or may forget the meaning of words.

Mixed dementia

Mixed dementia is a combination of two or more types of dementia.



The scale of the issue

Dementia is a growing problem which is affecting more and more people: there are currently over 850,000 people living with the condition in the UK, and this is expected to increase to 1.1 million by 2025, and 2 million by 2050.



Additionally:

- One in three people over the age of 65 will develop dementia. And as life expectancy increases, more and more people will be affected
- 225,000 people will develop dementia this year – that is one person every three minutes
- Dementia is the leading cause of death for women in England and Wales
- There are more than 40,000 people in the UK under the age of 65 who have dementia

The impact on families

There are an estimated 670,000 family members and friends acting as primary carers to someone with dementia. Caring for a loved one can become a full time role, meaning they might need to leave their jobs and see their lives change significantly. It can be very difficult for people to see their relationship change from that of a partner or spouse, friend or child, to that of a carer and a dependent. Often, they are not sure where to turn for information or support, and do not know what help and advice is available to them. High stress levels and depression are common amongst family carers.

This is why we believe that every family affected by the most complex dementia cases deserves access to the specialist support of an Admiral Nurse.

What does Dementia UK do?

Dementia UK provides specialist dementia support for families through our Admiral Nurse service.

When things get challenging or difficult for people with dementia and their families, Admiral Nurses work alongside them. They give the one-to-one support, guidance and practical solutions people need, and that can be hard to find elsewhere.

Admiral Nurses are continually trained, developed and supported by Dementia UK. Families that have their support have someone truly expert and caring by their side – helping them to live more positively with dementia in the present, and to face the challenges of tomorrow with more confidence and less fear.

We believe that everyone who needs the support of a specialist dementia nurse should get one, and we're working hard to increase the number of Admiral Nurses across the UK.

What is an Admiral Nurse?

An Admiral Nurse is a registered nurse who has extensive dementia experience, and the specialist knowledge and skills to support the most complex of family cases. They try and find solutions that others may not be in a position to consider – from identifying complex clinical issues which are linked to other medical conditions, to understanding the effects of medication, the impact of dementia on family relationships, and handling dementia-related behaviour which requires therapeutic support as well as a listening ear.

Admiral Nurses work with the whole family, but with a particular focus on the family caregiver to:

- Provide specialist clinical, practical, and social care advice; and emotional and psychological support from diagnosis to post-bereavement
- Help the family to manage their feelings and learn coping strategies
- Act as a single point of contact, joining up different parts of the complex health and social care system, and meeting people's needs in a co-ordinated way
- Share their knowledge so the family understands about dementia and its effect on both the person and the wider family
- Aid the family with the skills to enable them to communicate with someone living with dementia
- Offer advice on referrals to other services; and to liaise with health and social care professionals on a person's behalf, whilst sharing best practice so the person with dementia and their family get the best care possible
- Support people at difficult times, including when the condition progresses, or when hard decisions need to be made, such as moving a family member into residential care
- Provide support, and liaise with other professionals when end of life is approaching, and to continue with post bereavement support

How many people do Admiral Nurses support?

As Admiral Nurses work in such a wide range of settings, including NHS Trusts, mental health teams and community services (as well as care and nursing homes) and work with families with varying support needs, it can be difficult to put a definitive number on this. However, each Admiral Nurse has approximately 50 families on their caseload with whom they actively work. In addition, health and social care professionals in each of the areas where an Admiral Nurse service operates benefit from the expert consultation, advice and training that our nurses offer. As such, many more families living with dementia benefit from higher quality, more appropriate services and support. In 2018 our Admiral Nurses supported over 50,000 people.

What is the Admiral Nurse Dementia Helpline?

The Admiral Nurse Dementia Helpline is staffed by experienced Admiral Nurses and is available to anyone that needs guidance, practical advice or emotional support. From looking out for the first symptoms of dementia, to understanding the challenges of living with someone affected by dementia; our specialist Admiral Nurses have the knowledge and experience to understand the situation and suggest answers and lend support to those living with dementia, or caring for a loved one who has dementia.

You can call our Admiral Nurse Dementia Helpline on **0800 888 6678**

or send an email to helpline@dementiauk.org

Opening hours: **Monday – Friday 9am – 9pm**
Saturday and Sunday 9am – 5pm



Who is the Dementia Helpline for?

The people who most often contact us are families caring for someone with dementia, whether that be Alzheimer's disease, vascular dementia, or one of the rarer forms of dementia. But the Helpline is also available to people with a diagnosis of dementia, those worried about their memory or the memory of a loved one, and professionals working in dementia care. We're here for anyone who needs one-to-one support and practical solutions.

What happens when someone calls the Admiral Nurse Dementia Helpline?

Our Admiral Nurses will listen to the person and give advice and support. There's no time limit – many people call for more than half an hour – and can call back or email whenever they need us.



The other national dementia charities and what they do

Alzheimer's Society

Alzheimer's Society operates a network of one-to-one and group dementia services, including Dementia Advisors. These Dementia Advisors offer carers of people with dementia advice, support and signposting to local services, they differ from Admiral Nurses as they are non-clinical and do not possess the advanced training and expertise in the many complexities of dementia. Alzheimer's Society offers a range of information and advice through its publications, online forum, local groups and National Dementia Helpline, staffed by non-clinical Advisors. The charity also invests in research on care, cause, cure and prevention. Last year they invested 10% of their income (over £10m) in research and plan to invest a further £50m over the next five years.

Alzheimer's Research UK

Alzheimer's Research UK is dedicated to dementia research – to understand the causes, identify possible prevention strategies, treatments and cures for dementia.

What sets Dementia UK apart

Whilst other organisations have dementia advisers who offer valuable guidance to people with the condition and their families, Dementia UK's Admiral Nurses go beyond advice, offering the most comprehensive, specialist, expert service in the UK for families living with the complexities of dementia.



Admiral Nurses are all qualified nurses with a professional specialism in dementia. Their extensive clinical training and experience means they can support families and people with dementia through the most complex of situations such as offering advice on medication, on changing or worsening symptoms, and on therapeutic interventions.

Admiral Nurses start with a comprehensive assessment of each family they work with, to get a full picture of where they need help. They then offer tailored and flexible support, from advising families on the medical aspects of dementia, such as psychosis, incontinence and sleep disturbance, to

giving advice on improving family relationships that may be under stress. If someone with dementia has other physical health problems, Admiral Nurses can help manage these too.

Admiral Nurses can help co-ordinate a person's care, due to their understanding of the health and social care systems. They can advocate for families who might not know the best questions to ask, or who to ask them of, and can help families prepare for complicated processes such as continuing healthcare assessments or finding suitable long-term care.

Admiral Nurses focus on the family as a whole, including making sure carers have the support and skills they need. They equip carers with stress management techniques and coping strategies, and can help them to make contact with local respite services. They also provide specialist carer education and training.



Income 2017-18

Dementia UK	£6.9m
Alzheimer's Research UK	£18.2m
Alzheimer's Society	£106.9m
Macmillan Cancer Support	£252.7m
Cancer Research UK	£634.4m

Dementia UK has a considerably smaller income than the other two leading dementia charities, yet we are growing fast – our income has doubled over the past three years.

Despite being the primary cause of death in the UK, charitable support for dementia care and research is significantly behind that of cancer.

Dementia UK is funded by voluntary donations as we receive no government funding. In 2017/18, for every £1 we spent, 77p went on charitable activities and 23p on fundraising. We have invested significantly in fundraising in order to secure our future work.

How Admiral Nurse funding works

Many Admiral Nurses are based in host organisations within the NHS, charities or other organisations. Nurses are increasingly pump primed by Dementia UK i.e. half the Admiral Nurse salary is paid for by the charity for the first two years, in order to establish the role and embed it in the local community; with the agreement that the host organisation funds the role entirely after that.

How does Dementia UK spend the funds that are donated?

Dementia UK has a dedicated team who keep up-to-date with the latest developments and research in dementia in order to support Admiral Nurses across the country in their professional development and practice. They facilitate the sharing of knowledge and practice among the Admiral Nurses which is invaluable in the delivery of the care they offer. The team provides a professional competency framework and ongoing assessment against this, individual mentoring and support, monthly workshops, an annual national forum, facilitation of special interest groups or communities of practice and access to ongoing professional training.



Dementia UK also has a Business Development Team which is responsible for developing new Admiral Nurse services and maintaining current services, by fostering positive partnerships with host organisations and Clinical Commissioning Groups. In addition there is a clinics and awareness team who deliver training, one-to-one clinic sessions in a variety of settings and help to increase awareness and the need for more Admiral Nurses. The Business Development Team also works to expand the national telephone and email Helpline, the Admiral Nurse Dementia Helpline, which is open seven days a week and receives a high volume of calls.

How are services set up?

Each Admiral Nurse service is set up and operated as a partnership between Dementia UK and a host organisation. To develop an Admiral Nursing service within an area, a host organisation needs to agree to employ the Admiral Nurse / Nurses.

The majority of Admiral Nurses working face-to-face are within the NHS, supporting people in the community. However, they also work within a variety of settings within social and health services, voluntary organisations, hospices, hospitals and private care providers.



An Admiral Nurse can cost up to £50,000 a year to establish. Whilst this amount could be used to start a service and fund the first year, the sustainability of the post in future years would not be guaranteed, so this needs to be planned with a host organisation e.g. the NHS or a care provider.

In some cases, where the funds are available and it is a priority area (for instance where there are no Admiral Nurses), Dementia UK would offer to support some of the costs for a negotiated period of time. Dementia UK's portion of funding is raised through voluntary income including fundraising and donations.

How many Admiral Nurses are there?

Admiral Nurse Services are being discussed and developed all the time by our dedicated team. There are 264 Admiral Nurses in the UK supporting families living with the effects of dementia. However, we urgently need more and we aim to increase this number to 300 by the end of 2020, and ultimately to 800 across the UK – so we can ensure that everyone who needs the support of an Admiral Nurse has one.

Does Dementia UK pay its Admiral Nurses?

Admiral Nurses in the community, care homes, hospices and hospitals are paid by the host organisation – like the NHS, and charitable organisations.

The Admiral Nurses who work on the Admiral Nurse Dementia Helpline are paid by Dementia UK.



How can families get an Admiral Nurse?

We have a number of Admiral Nurse services across the country, which all have different referral processes, and some have specific criteria. You can see where there are Admiral Nurse Services by visiting: www.dementiauk.org/get-support/find-an-admiral-nurse

For areas which don't currently have an Admiral Nurse we have our Admiral Nurse Dementia Helpline – the only specialist dementia nurse Helpline in the country – which is open to anyone and is open seven days a week. The Helpline can be reached by emailing helpline@dementiauk.org or by calling **0800 888 6678**.

How can I fundraise for Dementia UK?

There are lots of ways that you can get involved in fundraising for Dementia UK. We have a series of running, trekking and cycling events if you would like to challenge yourself, and then some more relaxed activities like our Time for a Cuppa campaign which takes place in March each year. You can also put on your own event which we will support you with. For more inspiration you can find details of how to support us on our website www.dementiauk.org or by getting in touch with the fundraising team by emailing fundraising@dementiauk.org or calling **020 8036 5440**.



Do Volunteer Ambassadors get paid?

Volunteer Ambassadors aren't paid, but they are able to claim reasonable expenses for their travel and any other expenses incurred as part of their role. Often, our Ambassadors have had support themselves from an Admiral Nurse, and want to ensure that others can access this invaluable service by sharing their experience and voicing the impact a Nurse has had for them.



DementiaUK

Helping families face dementia

www.dementiauk.org

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Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).